Public Laws / Senate / Bills / 107th / 1st & 2nd Sessions / 2001-2002.

107TH CONGRESS
2D SESSION

S. 2489

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

IN THE SENATE OF THE UNITED STATES

MAY 9, 2002

Mrs. CLINTON (for herself, Ms. SNOWE, Ms. MIKULSKI, and Mr. BREAUX) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

---

A BILL

To amend the Public Health Service Act to establish a program to assist family caregivers in accessing affordable and high-quality respite care, and for other purposes.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the "Lifespan Respite Care Act of 2002".

SEC. 2. LIFESPAN RESPITE CARE.

The Public Health Service Act (42 U.S.C. 201 et seq.) is amended by adding at the end the following:

"TITLE XXVIII—LIFESPAN RESPITE CARE

"SEC. 2801. FINDINGS AND PURPOSES.

"(a) FINDINGS.—Congress finds that—

"(1) an estimated 26,000,000 individuals in the United States care each year for 1 or more adult family members or friends who are chronically ill, disabled, or terminally ill;

"(2) an estimated 18,000,000 children in the United States have chronic physical, developmental, behavioral, or emotional conditions that demand caregiver monitoring, management, supervision, or treatment beyond that required of children generally;

"(3) approximately 6,000,000 children in the United States live with a grandparent or other relative because their parents are unable or unwilling to care for them;

"(4) an estimated 165,000 children with disabilities in the United States live with a foster care parent;

"(5) nearly 4,000,000 individuals in the United States of all ages who have mental retardation or another developmental disability live with their families;

"(6) almost 25 percent of the Nation's elders experience multiple chronic disabling conditions that make it necessary to rely on others for help in meeting their daily needs;

"(7) every year, approximately 600,000 Americans die at home and many of these individuals rely on extensive family caregiving before their death;

"(8) of all individuals in the United States needing assistance in daily living, 42 percent are under age 65;

"(9) there are insufficient resources to replace family caregivers with paid workers;

"(10) if services provided by family caregivers had to be replaced with paid services, it would cost approximately $200,000,000,000 annually;

"(11) the family caregiver role is personally rewarding but can result in substantial emotional, physical, and financial hardship;

"(12) approximately 75 percent of family caregivers are women;

"(13) family caregivers often do not know where to find information about available respite care or how to access it;

"(14) available respite care programs are insufficient to meet the need and are directed at pri-

marily lower income populations and family caregivers of the elderly, leaving large numbers of family caregivers without adequate support; and

"(15) the limited number of available respite care programs find it difficult to recruit appropriately trained respite workers.

"(b) PURPOSES.—The purposes of this title are—

"(1) to encourage States to establish State and local lifespan respite care programs;

"(2) to improve and coordinate the dissemination of respite care information and resources to family caregivers;

"(3) to provide, supplement, or improve respite care services to family caregivers;

"(4) to promote innovative, flexible, and comprehensive approaches to—

"(A) the delivery of respite care;

"(B) respite care worker and volunteer recruitment and training programs; and

"(C) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services;

"(5) to support evaluative research to identify effective respite care services that alleviate, reduce,

or minimize any negative consequences of caregiving; and

"(6) to promote the dissemination of results, findings, and information from programs and research projects relating to respite care delivery, family caregiver strain, respite care worker and volunteer recruitment and training, and training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services.

"SEC. 2802. DEFINITIONS.

"In this title:

"(1) ASSOCIATE ADMINISTRATOR.—The term 'Associate Administrator' means the Associate Administrator of the Maternal and Child Health Bureau of the Health Resources and Services Administration.

"(2) CONDITION.—The term 'condition' includes—

"(A) Alzheimer's disease and related disorders;

"(B) developmental disabilities;

"(C) mental retardation;

"(D) physical disabilities;

"(E) chronic illness, including cancer;

"(F) behavioral, mental, and emotional conditions;

"(G) cognitive impairments;

"(H) situations in which there exists a high risk of abuse or neglect or of being placed in the foster care system due to abuse and neglect;

"(I) situations in which a child's parent is unavailable due to the parent's death, incapacitation, or incarceration; or

"(J) any other conditions as the Associate Administrator may establish by regulation.

"(3) ELIGIBLE RECIPIENT.—The term 'eligible recipient' means—

"(A) a State agency;

"(B) any other public entity that is capable of operating on a statewide basis;

"(C) a private, nonprofit organization that is capable of operating on a statewide basis;

"(D) a political subdivision of a State that has a population of not less than 3,000,000 individuals; or

"(E) any recognized State respite coordinating agency that has—

"(i) a demonstrated ability to work with other State and community-based agencies;

"(ii) an understanding of respite care and family caregiver issues; and

"(iii) the capacity to ensure meaningful involvement of family members, family caregivers, and care recipients.

"(4) FAMILY CAREGIVER.—The term 'family caregiver' means an unpaid family member, a foster parent, or another unpaid adult, who provides in-home monitoring, management, supervision, or treatment of a child or adult with a special need.

"(5) LIFESPAN RESPITE CARE.—The term 'lifespan respite care' means a coordinated system of accessible, community-based respite care services for family caregivers of individuals regardless of the individual's age, race, ethnicity, or special need.

"(6) RESPITE CARE.—The term 'respite care' means planned or emergency care provided to an individual with a special need—

"(A) in order to provide temporary relief to the family caregiver of that individual; or

"(B) when the family caregiver of that individual is unable to provide care.

"(7) SPECIAL NEED.—The term 'special need' means the particular needs of an individual of any age who requires care or supervision because of a condition in order to meet the individual's basic needs or to prevent harm to the individual.

"SEC. 2803. LIFESPAN RESPITE CARE GRANTS AND COOPERATIVE AGREEMENTS.

"(a) PURPOSES.—The purposes of this section are—

"(1) to expand and enhance respite care services to family caregivers;

"(2) to improve the statewide dissemination and coordination of respite care; and

"(3) to provide, supplement, or improve access and quality of respite care services to family caregivers, thereby reducing family caregiver strain.

"(b) AUTHORIZATION.—Subject to subsection (f), the Associate Administrator is authorized to award grants or cooperative agreements to eligible recipients who submit an application pursuant to subsection (d).

"(c) FEDERAL LIFESPAN APPROACH.—In carrying out this section, the Associate Administrator shall work in cooperation with the National Family Caregiver Support Program Officer of the Administration on Aging, and respite care program officers in the Administration for Children and Families, the Administration on Develop-

mental Disabilities, and the Substance Abuse and Mental Health Services Administration, to ensure coordination of respite care services for family caregivers of individuals of all ages with special needs.

"(d) APPLICATION.—

"(1) SUBMISSION.—Each eligible recipient desiring to receive a grant or cooperative agreement under this section shall submit an application to the Associate Administrator at such time, in such manner, and containing such information as the Associate Administrator shall require.

"(2) CONTENTS.—Each application submitted under this section shall include—

"(A) a description of the applicant's—

"(i) understanding of respite care and family caregiver issues;

"(ii) capacity to ensure meaningful involvement of family members, family caregivers, and care recipients; and

"(iii) collaboration with other State and community-based public, nonprofit, or private agencies;

"(B) with respect to the population of family caregivers to whom respite care information or services will be provided or for whom respite

care workers and volunteers will be recruited and trained, a description of—

"(i) the population;

"(ii) the extent and nature of the respite care needs of the population;

"(iii) existing respite care services for the population, including numbers of family caregivers being served and extent of unmet need;

"(iv) existing methods or systems to coordinate respite care information and services to the population at the State and local level and extent of unmet need;

"(v) how respite care information dissemination and coordination, respite care services, respite care worker and volunteer recruitment and training programs, or training programs for family caregivers that assist such family caregivers in making informed decisions about respite care services will be provided using grant or cooperative agreement funds;

"(vi) a plan for collaboration and coordination of the proposed respite care activities with other related services or pro-

grams offered by public or private, nonprofit entities, including area agencies on aging;

"(vii) how the population, including family caregivers, care recipients, and relevant public or private agencies, will participate in the planning and implementation of the proposed respite care activities;

"(viii) how the proposed respite care activities will make use, to the maximum extent feasible, of other Federal, State, and local funds, programs, contributions, other forms of reimbursements, personnel, and facilities;

"(ix) respite care services available to family caregivers in the applicant's State or locality, including unmet needs and how the applicant's plan for use of funds will improve the coordination and distribution of respite care services for family caregivers of individuals of all ages with special needs;

"(x) the criteria used to identify family caregivers eligible for respite care services;

"(xi) how the quality and safety of any respite care services provided will be monitored, including methods to ensure that respite care workers and volunteers are appropriately screened and possess the necessary skills to care for the needs of the care recipient in the absence of the family caregiver; and

"(xii) the results expected from proposed respite care activities and the procedures to be used for evaluating those results; and

"(C) assurances that, where appropriate, the applicant shall have a system for maintaining the confidentiality of care recipient and family caregiver records.

"(e) REVIEW OF APPLICATIONS.—

"(1) ESTABLISHMENT OF REVIEW PANEL.—The Associate Administrator shall establish a panel to review applications submitted under this section.

"(2) MEETINGS.—The panel shall meet as often as may be necessary to facilitate the expeditious review of applications.

"(3) FUNCTION OF PANEL.—The panel shall—

"(A) review and evaluate each application submitted under this section; and

"(B) make recommendations to the Associate Administrator concerning whether the application should be approved.

"(f) AWARDING OF GRANTS OR COOPERATIVE AGREEMENTS.—

"(1) IN GENERAL.—The Associate Administrator shall award grants or cooperative agreements from among the applications approved by the panel under subsection (e)(3).

"(2) PRIORITY.—When awarding grants or cooperative agreements under this subsection, the Associate Administrator shall give priority to applicants that show the greatest likelihood of implementing or enhancing lifespan respite care statewide.

"(g) USE OF GRANT OR COOPERATIVE AGREEMENT FUNDS.—

"(1) IN GENERAL.—

"(A) MANDATORY USES OF FUNDS.—Each eligible recipient that is awarded a grant or cooperative agreement under this section shall use the funds for, unless such a program is in existence—

"(i) the development of lifespan respite care at the State and local levels; and

"(ii) an evaluation of the effectiveness of such care.

"(B) DISCRETIONARY USES OF FUNDS.—Each eligible recipient that is awarded a grant or cooperative agreement under this section may use the funds for—

"(i) respite care services;

"(ii) respite care worker and volunteer training programs; or

"(iii) training programs for family caregivers to assist such family caregivers in making informed decisions about respite care services.

"(C) EVALUATION.—If an eligible recipient uses funds awarded under this section for an activity described in subparagraph (B), the eligible recipient shall use funds for an evaluation of the effectiveness of the activity.

"(2) SUBCONTRACTS.—Each eligible recipient that is awarded a grant or cooperative agreement under this section may use the funds to subcontract with a public or nonprofit agency to carry out the activities described in paragraph (1).

"(h) TERM OF GRANTS OR COOPERATIVE AGREEMENTS.—

"(1) IN GENERAL.—The Associate Administrator shall award grants or cooperative agreements under this section for terms that do not exceed 5 years.

"(2) RENEWAL.—The Associate Administrator may renew a grant or cooperative agreement under this section at the end of the term of the grant or cooperative agreement determined under paragraph (1).

"(i) SUPPLEMENT, NOT SUPPLANT.—Funds made available under this section shall be used to supplement and not supplant other Federal, State, and local funds available for respite care services.

"(j) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section—

"(1) $90,500,000 for fiscal year 2003;

"(2) $118,000,000 for fiscal year 2004;

"(3) $145,500,000 for fiscal year 2005;

"(4) $173,000,000 for fiscal year 2006; and

"(5) $200,000,000 for fiscal year 2007.

CMS LIBRARY
3 8095 00017626 9

"SEC. 2804. NATIONAL LIFESPAN RESPITE RESOURCE CENTER.

"(a) ESTABLISHMENT.—From funds appropriated under subsection (c), the Associate Administrator shall award a grant or cooperative agreement to a public or private nonprofit entity to establish a National Resource Center on Lifespan Respite Care (referred to in this section as the 'center').

"(b) PURPOSES OF THE CENTER.—The center shall—

"(1) maintain a national database on lifespan respite care;

"(2) provide training and technical assistance to State, community, and nonprofit respite care programs; and

"(3) provide information, referral, and educational programs to the public on lifespan respite care.

"(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section $500,000 for each of fiscal years 2003 through 2007.".

○